

Enhancing secondary use of health data  
across the Nordic countries:

# The Nordic Commons project

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# Nordic Strengths in the Health Area

The Nordic countries share synergistic factors that make the region attractive for research and innovation:

- similar health care systems available to all citizens
- publicly funded universities
- established research networks
- citizens have trust in research and authorities collecting data
- population of +27 Million

Long history of Nordic cooperation between scientists and political stakeholders



# Health Data – a Nordic Goldmine

- Each Nordic country have similar health data sources collected by health care, authorities, research and patients/individuals
- Register-, biobank-, genomics-, survey data
- The personal identification number allows linkage
- Data “from the cradle to the grave”



Photo by [Alexander Sinn](#) on [Unsplash](#)



# Health and Welfare: a Nordic research priority

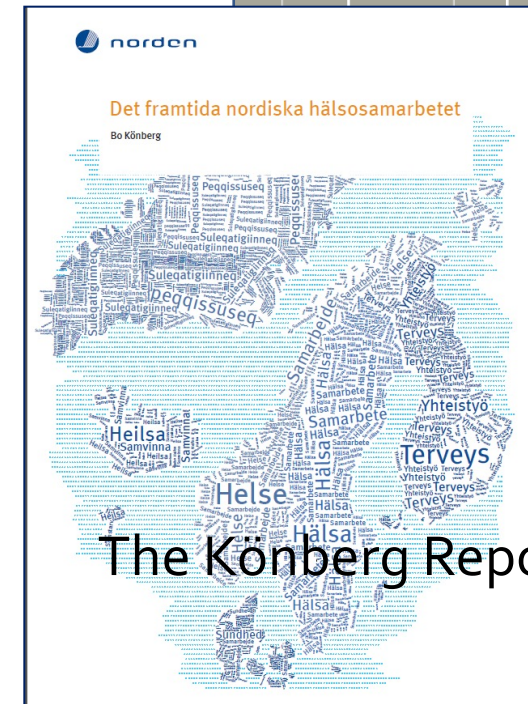
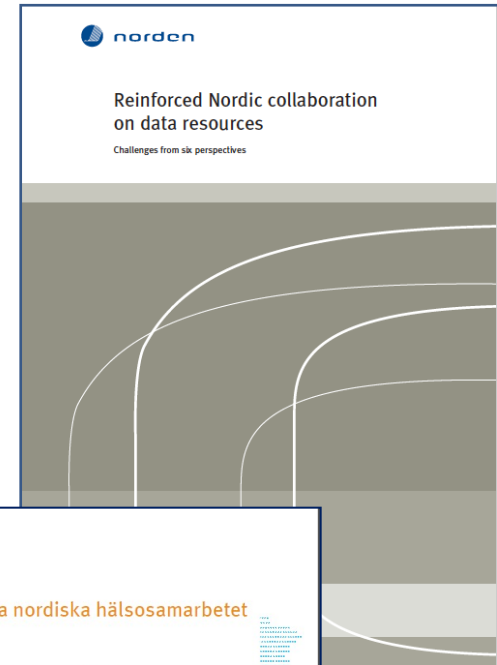
- NordForsk – Nordic institution that funds research and research infrastructure cooperation
- Major investments in health research (MEUR 50+)
- Co-funded by all Nordic countries
- Focus on exploiting the Nordic strategic data resources – registers and biobanks – in research
- Data acquisition processes are time-consuming, includes many permits and issues of comparability



# A Nordic Political Priority

- An NCM report shed light on challenges impeding Nordic register data utilization already in 2012
- The Könberg report proposed a Nordic virtual center for register-based research in 2014
- 2017 and 2022: the Norwegian Presidency puts focus on Nordic cooperation on health data
- The Nordic Council of Ministers **Vision 2030** – the Nordic Commons included in the Action Plan 2021-2024.

Marie Sandberg, CSC, Nordic Council of Ministers  
TemaNord 2012:514



The Könberg Report 2014



# How to Reach the Nordic Potential?

- NordForsk coordinated a Nordic effort to identify ways of improving secondary use of health data in research
- Funding from the Norwegian Presidency Programme 2017-2019
- Task Forces on metadata, technology and legislation/ethics
- Recommendations were presented to EK-S, EK-U and Nordic Research Funders in 2020



A VISION OF A NORDIC SECURE  
DIGITAL INFRASTRUCTURE  
FOR HEALTH DATA:  
**THE NORDIC COMMONS**

 NordForsk

<https://www.nordforsk.org/publications>

# Vision for the Nordic Commons

“The Nordic region as a leading region for secondary use of health data”

This would require:

1. Nordic health data described with rich metadata according to the FAIR\* criteria – a **federated Nordic Health Metadata Repository**
2. A Nordic **federated secure infrastructure** for processing sensitive personal data
3. A coherent **legal and ethical framework** supporting the above
4. A **funding programme** for technology and competence development (proof-of-value)



\* Findable, Accessible, Interoperable, Re-usable

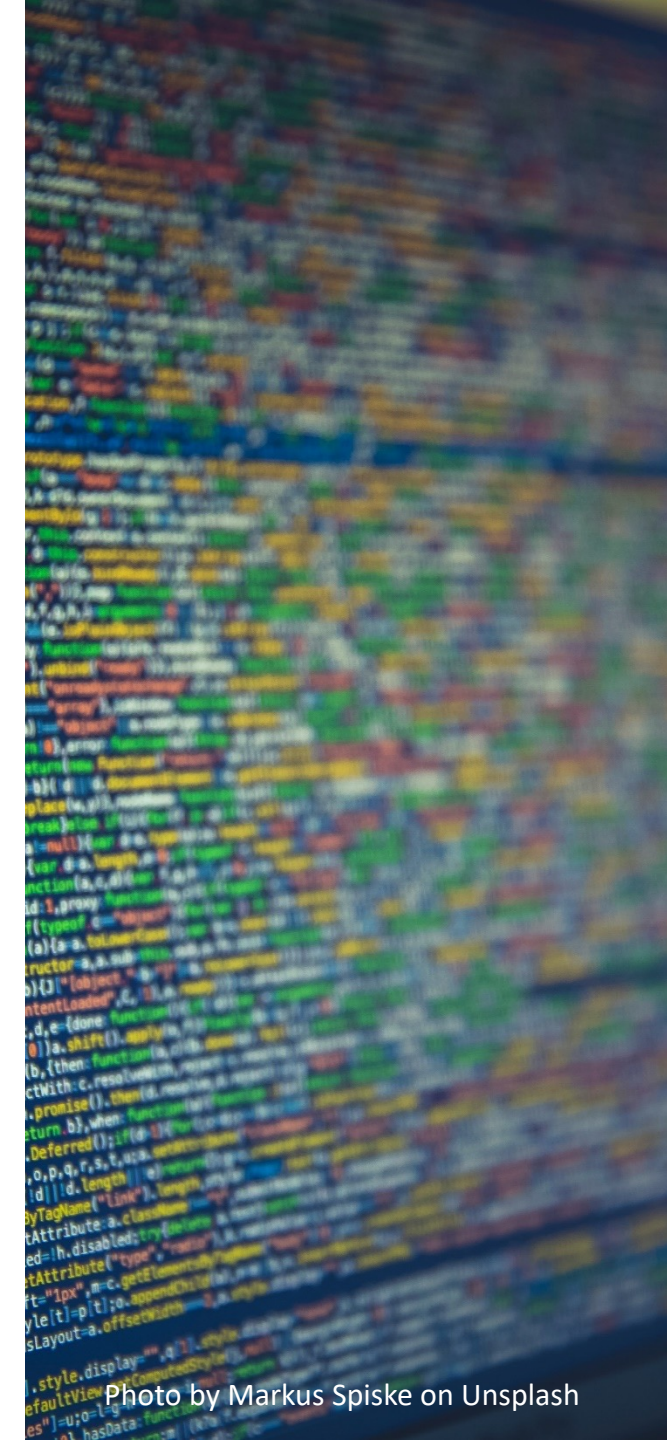


Photo by Markus Spiske on Unsplash

# Recommendations

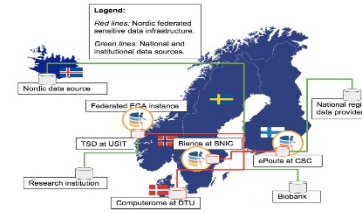
- A. To establish a **high-level policy board** comprised of national actors from the health, research and innovation sectors.
- aligning national initiatives
  - access to resources
  - promote funding mechanisms and calls
  - support of development, proof-of-value projects
  - establish future governance
- B. To secure **sustainable funding** from national and Nordic research/innovation and research infrastructure funders.
- support research to test, utilise and contribute to the Nordic Health Data technology solution and to the Nordic metadata standards framework.*





# Recommendations (continued)

C. To establish a **technology expert group** comprised of national representatives of digital infrastructures on health data.



- ❑ outlining the *design and implementation of a Nordic Health Cloud*
- ❑ setting up use-cases/proof of values

D. To establish a **metadata expert group** comprised of the national health data hosting organisations and relevant national metadata initiatives.

Domain	Denmark	Finland	Norway	Sweden	Iceland
Health Register	DK	FI	NO	SE	IS
Clinical Quality Register	DK	FI	NO	SE	IS
Biobanks	DK	FI	NO	SE	IS
OMICS	DK	FI	NO	SE	IS
Laboratory Data	DK	FI	NO	SE	IS
Health Economic/Policy Studies	DK	FI	NO	SE	IS
Epidemiology Registers	DK	FI	NO	SE	IS

- ❑ *set up a Nordic health metadata repository ecosystem*
- ❑ i.e. a digitalised system for data documentation using established standards.

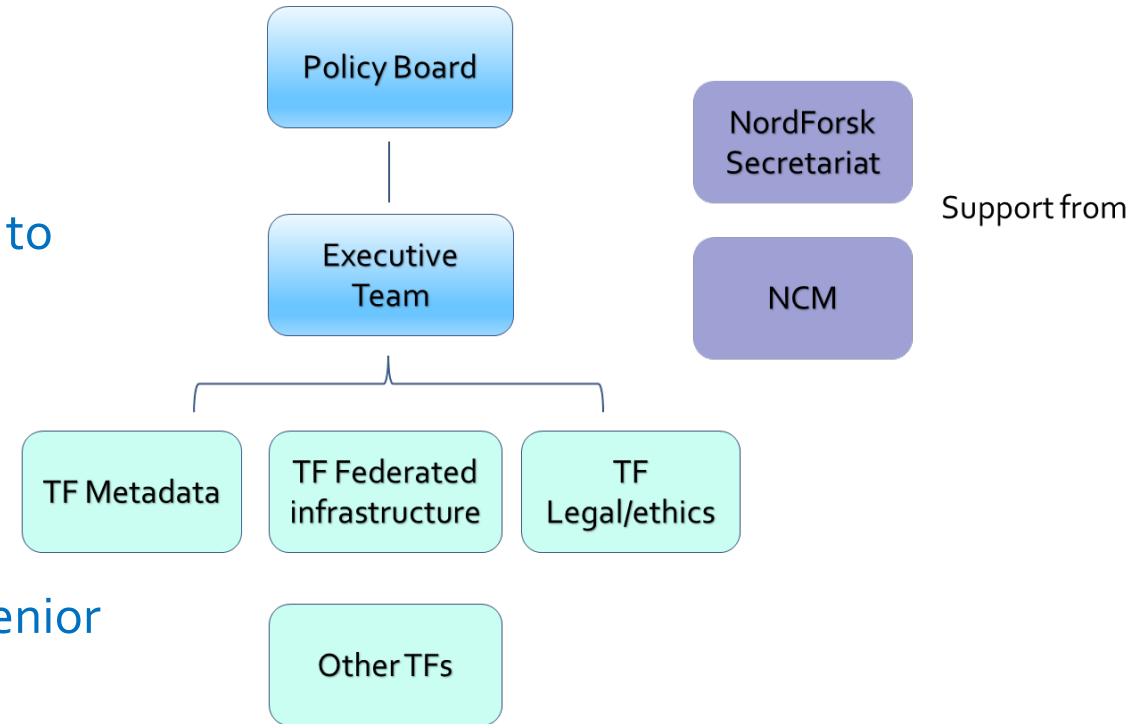
E. To establish an **expert group on legislation, ethics and trust** comprised of competencies in and perspectives on international legislation and policies.

- ❑ *national legislation should meet the technology demands of the Nordic Health Cloud.*



# The project has been kicked-off

- The Nordic Commons Project has been funded with appr. MEUR 3 (22 MDKK) between 2021-2024
- NordForsk tasked to provide administrative support to Policy Board and coordinating function
- Norway and Finland Lead countries
- Mandate for Policy Board, Executive Team and NordForsk decided by EK-S (Nordic Committee of Senior Officials from Health Ministries)
- Nordic countries have appointed members to Policy Board and Executive Team. Chair appointed early February. Policy Board met in March. Task Forces nominated.



# Policy Board

- **Denmark:** Lisa Bredgaard, Jan Poulsen, The Danish Health Data Authority
- **Finland:** Jukka Lähesmaa, Ministry of Social Affairs and Health, Sirpa Soini, Finnish Institute for Health and Welfare
- **Iceland:** Unnur Anna Valdimarsdóttir, University of Iceland, Helga Ágústsdóttir Ministry of Health
- **Sweden:** Michel Silvestri, Swedish eHealth Agency, NN, Ministry of Health and Social Affairs
- **Norway:** Irene Olaussen, Ministry of Health and Care Services, Håvard Kolle Riis, The Norwegian Directorate of eHealth
- **NordForsk Board:** Jonas Björck, Secretary General Forte (Chair)
  
- **Nordic Council of Ministers Secretariat:** Anne Camilla Hilton
- **NordForsk:** Maria Nilsson



# Executive Team

- **Denmark:** Jan Poulsen, The Danish Health Data Authority
- **Finland:** Persephone Doupi, Finnish Institute for Health and Welfare
- **Iceland:** Sigríður Haralds Elínardóttir, The Directorate of Health
- **Sweden:** John Kling, The National Board of Health and Welfare
- **Norway:** Karoline Kristensen/Christina Hilmarsen, The Norwegian Directorate of eHealth
  
- **Nordic Council of Ministers Secretariat:** Anne Camilla Hilton
- **NordForsk:** Maria Nilsson

# Metadata, Data Quality and Semantics Task Force

**Denmark:** Eva Sandberg, OPEN Patient data Explorative Network

**Finland:** Mari Mäkinen/ Minna Liikala, Finnish Institute for Health & Welfare (THL)

**Iceland:** Guðrún Kr. Guðfinnsdóttir, Icelandic Directorate of Health

**Norway:** Truls Korsgaard, Norwegian Directorate for e-Health (Co-Chair)

**Sweden:** Zoltan Thinz, National Board of Health and Welfare

**Executive Team:** Sigríður Haraldsd Elínardóttir, Iceland (Chair)



# Federated Infrastructure Task Force

**Denmark:** Ali Syed and Majbrit Fonnesbæk Hansen, Danish National Genome Center

**Finland:** Juha Törnroos, CSC IT Centre for Science (Chair) and Gustav Klingstedt, THL

**Iceland:** Hólmfríður G. Pálsdóttir, Icelandic Directorate for Health

**Norway:** Olav Astad Kristiansen, Norwegian Directorate for e-Health

**Sweden:** Manne Andersson, Swedish eHealth Agency

**Executive Team:** Persephone Doupi (Co-Chair), Finland



# Legislation, Ethics and Trust Task Force

**Denmark:** Sigrun Gyrtrup, Danish Health Data Authority

**Finland:** Inkeri Helenius and Heli Geitlin, Finnish Institute for Health and Welfare (THL)

**Iceland:** Hólmur Örn Finnsson, Icelandic Directorate of Health

**Norway:** Inger Lise Neeraas, Norwegian Directorate for e-Health

**Sweden:** Victoria Söderqvist, Swedish Research Council

**Executive Team:** John Kling (Chair), Sweden



# Value beyond the Nordics

- Activities under the Nordic Commons have great potential to also have impact on the international arena
- Regional cooperation could develop proof-of-value for Europe
  - based on Nordic health data
  - Nordic pilot for the European Health Data Space
- Essential to involve key national actors and to consolidate the work nationally
- Focus of 2022 is to set up Task Forces and use-cases



Photo by Chang Duong  
on Unsplash



**Thank you for your attention!**

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